

# Providing Structured Opportunities for Nursing Home Residents to Choose Community Care

The assumption of the inevitability of nursing home placement is convenient for facility personnel, attending professionals, and even family members. Families in particular may resist revisiting a decision that is often agonizing in the first place. But the article by Christy M. Nishita and colleagues in this issue<sup>1</sup> refutes the contention that few elderly long-stay nursing home residents would choose to return to the community. The authors approached the topic head-on—in a small, carefully designed study, they asked the residents or their proxy spokespersons a series of direct questions. They found that 23% of respondents believed that the resident could make a successful transition to the community and that 46% expressed a preference to return to that community. After the residents received information about housing and services in the community, the percentage saying that the resident could make a successful transition went up to 33%, suggesting that the receipt of structured information changed choices. A test–retest interrater reliability study showed that the responses on this screening questionnaire were stable. The authors also compared the responses they received from the direct approach with responses on the single item in Section Q of the Minimum Data Set (MDS) 2.0, which asks the MDS assessor to judge whether the resident wishes to be discharged from the nursing home. The MDS responses were incongruent with those of the investigators, and the MDS results identified fewer who wanted to leave than did the direct interview. Using the inferred MDS data in lieu of actually asking the residents about their preferences for leaving is a pity. Research has shown that residents whose recent MDS cognitive scores are poor can respond reliably to questions about their preferences.<sup>2,3</sup>

The results have implications for assessment of residents. As the authors point out, the MDS is flexible about how assessors gather the information to complete it. For Question Q, the MDS manual even provides a paternalistic nudge by advising against disturbing a long-stay resident or raising unrealistic expectations and suggesting a subtle approach with leading questions such as “It’s been about 1 year that we’ve known each other. How are things going for you here at (name of nursing home)?” Nobody who takes a data collection instrument seriously could endorse this approach to eliciting a preference for remaining at the nursing home or moving out. Research neophytes are taught to ask their questions clearly, directly, and consistently, without skipping questions or rewording them.<sup>4</sup> The MDS is not a

questionnaire per se but rather a data collection tool for recording clinical judgments, and this example illustrates biases inherent in unscripted assessments. An analogy can be made to the way physicians and others historically approached eliciting end-of-life preferences by using oblique and indirect questions rather than openly engaging the subject, a phenomenon also noted when professionals assess suicidal ideation, sexuality, or incontinence in older people. Information is improved if professionals use standardized assessments such as have been developed for assessing preferences at the end of life<sup>5</sup> or even a single clear item. In the case of suicidal ideation, the question “How often have you thought about killing yourself?” was posed to a large group of nursing home residents without unduly upsetting anyone and eliciting information that about 10% of residents think about it all the time.<sup>6</sup> One cannot assess a possibly sensitive topic through avoidance. Moreover, residents typically welcome open discussions of their fears and concerns. If a resident is actively and deeply upset about being in a nursing home, assessors need not worry that their question will remind the resident of this misery. The problem upsetting the resident is not the assessment question, but the fact of being in the nursing home and his/her experiences there.

The MDS 3.0, now in the testing phase, includes new sections asked directly of residents, including a direct depression measure. These changes are a major advance, although it would be important not to disqualify too many respondents from direct interviews based on judgments about their cognitive abilities. In general, professional assessors worry too much about getting biased information because of inaccurate responses from older people who may deny their problems or fail to recall the information but too little about biases from their own omissions of questions and inferences about the answers.

Over the last 5 years, advocates for community care have become aware of Section Q, a previously little-analyzed component of the MDS. They began counting and publicizing the responses in a simple state-by-state report on the proportion of residents wanting to move out. As often occurs with unanalyzed items in long assessment batteries, quality of the data was poor and the item often left blank. Despite that, the percentages of all residents whose MDS indicates a wish to move out is more than 10% in most states, and sometimes up to one-quarter of the responses are affirmative. Some states have made aggregate Section Q results available according to facility and have shared actual data with transition counselors who act as

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agents of the state. The State of Texas, which has led the way in allowing Medicaid money to follow a person (MFP) out of the nursing home, has amassed considerable experience using Section Q data to guide transition programs. State officials find it a good start, although further exploration identifies false positives and false negatives. Between 2001 and 2006, the Texas MFP initiative helped 11,300 nursing facility residents transition to the state's Home- and Community-Based Services waivers, two-thirds of whom were elderly and many very old.<sup>7,8</sup>

Considerable work is being done to test revisions of Section Q and related instructions so as to gain a more-accurate reflection of resident preference. One of the key points is to avoid confounding the judgment of feasibility made by caregivers from the eliciting of consumer preferences.

Community care is now a distinct possibility for many elderly nursing home residents. The MFP demonstration, authorized in 2005, allows the 30 participating states and the District of Columbia a much more generous federal Medicaid match to purchase services during the first year that the long-stay nursing home resident is in the community, thus permitting a shoring up of the community plan. The Centers for Medicare and Medicaid Services (CMS) has also clarified that transition expenses may be covered under Medicaid waivers, which is important, because resident income goes to pay nursing homes in advance for the current month, and many would-be leavers would be unable to afford their security deposits, advance rent, linens, and furnishings without transition funding.

The 1999 Supreme Court *Olmstead* decision ruled that, under the Americans with Disability Act (ADA), people should not be required to live in institutions to meet their medical needs and encouraged states to develop plans to enable long-term care consumers to live in the most integrated setting possible. The presidential New Freedom Initiative of 2001 and the Real Choice System Change Grants awarded by CMS every year thereafter have encouraged states to develop an infrastructure to permit efficient, high-quality care in the community and allow seniors to make a choice. The initial energy behind the New Freedom efforts was by and on behalf of younger people with disabilities, yet almost every elderly nursing home resident qualifies as having a disability under the ADA, and cross-disability efforts to form coalitions between people with all types of disabilities of all ages are having some success.<sup>9</sup>

Many states are searching for the ideal assessment or screening tool to identify those who can safely make transitions. The article appearing here accentuates the importance of asking residents and families their opinions and doing so in a way that offers them information to help them structure their choices. This study is strengthened, because it included people with Alzheimer's disease in the samples. No assumptions were made about resident and family preferences *a priori*.

Choice is the mantra of the New Freedom Initiative, but a true choice must meet some criteria. It should be made freely (that is, without coercion) by people who have one or more options and information about those options and are capable of weighing the options against their own preferences. Models for helping older people and their families work through structured decisions about long-term care

have now have been tested.<sup>10</sup> The State of Arkansas passed a statute in April 2007 that required options counseling to be offered to all nursing home residents unless they explicitly refused the opportunity to learn about choices.

Perhaps not coincidentally, the same post-Olmstead period that has opened up a hope for elderly people who want to leave nursing homes has also been a period of unusual activity to improve life in nursing homes in terms of physical amenities and privacy, individualized care, and an emphasis on resident self-direction and quality of life.<sup>11</sup> Physicians, nurses, social workers, therapists, and all who labor in the nursing home are challenged to promote this emphasis, which is summarized under the banner of culture change. Nursing homes will always be a reasonable choice for some individuals, and the movement toward transforming them into livable communities is to be applauded, but these same professionals are simultaneously challenged to assist those residents who wish to move out. Professionals from outside the nursing home are coming in to offer help with the details of arrangements for community living. This outside impetus is surely necessary, because nursing home staff can hardly be expected to work vigorously to help formerly long-stay residents exercise the choice to return to the community, on the one hand, while, on the other hand, transforming nursing homes into positive living environments where residents might want to stay. Working on two such different new directions simultaneously risks cognitive dissonance for nursing home staff. Yet if collaboration between nursing home staff, external transition counselors, and community caregivers were to occur, transition programs could occur more readily and with more assurance of continuity of needed health care. As professionals who are not typically employed by the nursing homes, medical directors, attending physicians, and other ambulatory care personnel are in an especially good position to play a bridging role in helping residents return to the community. Then the next step for physician and nurse leadership will be to restructure primary care and postacute care so that some older people can be diverted from unwanted long stays in nursing homes.

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